H.R. 5555 -- The Personalize Your Care Act 2.0

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The last five years have seen amazing advances in end-of-life care. As of January 2016, advance care planning is a Medicare benefit. For the first time, providers will be reimbursed for the time necessary to have these complex conversations with patients and their families. Documents like advance directives and physician orders for life sustaining treatment are a first step in providing high-quality, personalized care, but more must be done to ensure patients receive care at the end of life that is consistent with their stated goals, values, and informed preferences.

SUMMARY OF THE LEGISLATION:

The *Personalize Your Care Act 2.0* aims to strengthen end-of-life care by promoting a new advanced illness management model of care. Care models that integrate palliative care and supporting services provide high-quality end-of-life care and reduce the use of avoidable hospital- and institution-based services that patients may not want. This Demonstration Project would establish a new Medicare model that provides concurrent care choices in addition to hospice care; a functional assessment of the individual; in-home services and supports; 24/7 emergency supports; and promotes the early use of palliative care services.

The bill also provides grants to states to establish or expand programs for orders for life sustaining treatment programs, which have a positive record of promoting patient autonomy through documenting and coordinating a person's treatment preferences, and would provide grants to develop additional decision support tools for individuals, caregivers, and providers that include the importance articulating goals of care, developing a care plan, and documentation.

Additionally, the bill improves the accessibility and portability of advance care planning documents by ensuring that an individual's electronic health record displays the current advance directive and/or physician orders for life sustaining treatment so that the patient's goals, values, and preferences would be more readily known.

This bill also provides resources to enhance provider training. All clinicians who care for people with advanced serious illness should be competent in basic advance care planning and palliative care, including culturally appropriate communication skills, inter-professional collaboration, and symptom management. At the same time, this bill provides resources to develop patient and family decision support tools that present the importance of articulating goals of care, understanding disease prognosis, and developing and documenting a care plan.

Finally, the bill directs the Secretary of Health and Human Services to develop end-of-life quality measures that consider patient and family goals, preferences, and values, including the articulation of goals that reflect how the patient wants to live; consistency among a patients goals, values, and preferences, and the outcome of the treatment; and the accessibility of advance care plans across all care settings. These quality measures would work with the development of current alternative payment models and payment reforms such as the Medicare Access and CHIP Reauthorization Act (MACRA).

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SECTION-BY-SECTION

Sec. 1: Findings

Sec. 2: Advanced Illness Management and Choices Demonstration

Care models that integrate palliative care and supporting services provide high-quality end-of-life care and reduce the use of avoidable hospital- and institution-based services that patients may not want. This Demonstration Project would establish a new Medicare model that provides concurrent care choices in addition to hospice care; a functional assessment of the individual; in-home services and supports; 24/7 emergency supports; and promotes the early use of palliative care services.

Sec. 3: Grants to Establish or Expand Programs for Orders for Life Sustaining Treatment Programs

Physician orders for life sustaining treatment (POLST) programs, and other programs by similar names, help seriously ill patients identify their treatment preferences using a clear, standardized template. Written as actionable medical orders, these forms help communicate patient preference regarding intensity of medical intervention and are recognized in all care settings.

Sec. 4: Inclusion of Advance Directives and POLST in the Electronic Health Record

Including completed advance care planning documents within a patient's electronic health record increases the likelihood these documents are kept up-to-date and available in the right place at the right time. Current regulation and certification standards only require the indication of whether a patient has an advance directive, not the actual content or one-click access to the advance directive.

Sec. 5: Portability of Advance Directives

Advance directives should follow the patient; regardless of the state or site of care. This section also directs the Comptroller General to study the use, portability, and electronic storage of advance directives, including issues that remain unresolved after the Stage 3 Meaningful Use final rule.

Sec. 6: Quality Measures Related to End-of-Life Care

Directs the Secretary to incorporate quality measures related to end-of-life care under the Medicare Access and CHIP Reauthorization Act (MACRA) and Improving Medicare Post-Acute Care Transformation Act (IMPACT) reforms.

Sec. 7: Annual Report of Medicare Decedents

Requires the Secretary to issue an annual report that analyzes the care or payer settings at the time of death; demographics and geographic information of Medicare decedents; and an evaluation of Medicare claims data for services furnished in the last year of life.

Sec. 8: Increasing Public Awareness for Advance Care Planning

Grants under this section would provide for the development of decision support tools and instructional materials for individuals and family caregivers articulating the importance of formulating goals of care, understanding disease prognoses, and documenting care plans.

Sec. 9: Advance Care Planning and Palliative Care Education and Training

Resources provided under this section would provide for such training and professional development for clinicians who care for people with advanced serious illness.

Sec. 10: Advance Care Planning Advisory Council

Establishes an Advisory Council to the Secretary on issues of advanced and terminal illness.